



## [NAMI SCC Website](#)

# Mental Health Recovery: What Helps and What Hinders?

*The following comes courtesy of OMH's Doug Dornan:*

### **Mental Health Recovery: What Helps And What Hinders? A National Research Project For The Development Of Recovery Facilitating System Performance Indicators**

The National Research Project for the Development of Recovery Facilitating System Performance Indicators is proud to announce the release of Phase One Research: A National Study of Consumer Perspectives on What Helps and Hinders Recovery (Release Date: Mid October 2002).

Home

A team of consumer and non-consumer researchers, nine state mental health authorities, and a consortium of sponsors are working to operationalize a set of health system performance indicators based on the lived experience of persons with psychiatric disabilities as to what helps and what hinders them in their recovery. One of the research project was designed to identify the resources, processes (choice), qualities (such as hope), relationships, mental health services, and environments that influence recovery.

About

Links

Search

Alerts

Editorial

Experiences

This research used a grounded theory approach concerning the phenomenon of recovery and the ways in which the social environment, including the mental health system, impacts the process. Consumer/survivors in ten focus groups across nine states provided in depth knowledge and experience concerning both the obstacles and supports for recovery from their general environment and within the mental health system. The Phase One Research Report conveys the results of this research in design, cross-site findings, discussion and implications.

News

This report significantly contributes to the developing knowledge base on mental health recovery, in particular, expanding our understanding of the dynamic, ecological of factors that facilitate or impede recovery. This report strengthens the foundation which to develop performance indicators and evaluation instruments to assess the recovery orientation of mental health services and systems.

Newsletters

People

#### **RESEARCH TEAM:**

Steven J. Onken, Ph.D.; Jeanne M. Dumont, Ph.D.; Priscilla Ridgway, M.S.W., / Douglas H. Dornan, M.S.; Ruth O. Ralph, Ph.D.

Recovery

#### **PARTICIPATING STATES:**

Arizona, Colorado, New York, Oklahoma, Rhode Island, South Carolina, Texas, Washington

Research

Santa Cruz

#### **SPONSORS:**

CMHS, Colorado Mental Health Services, Columbia University Center for the Study of Social Work Practice, HSRI, Missouri Institute of Mental Health, The Center for Issues in Public Mental Health, NASMHPD, New York State Office of Mental Health, Oklahoma Department of Mental Health & SAS

Sitemap

## Guest Book

To obtain a free copy of Phase One Research Report: A National Study of Consumer Perspectives on What Helps and Hinders Recovery, contact:

Ieshia Haynie  
National Technical Assistance Center for State Mental Health Planning  
66 Canal Center Plaza, Suite 302, Alexandria, VA 22314  
Phone: (703) 739-9333; Fax: (703) 548-9517  
General inquiries: [ntac@nasmhpd.org](mailto:ntac@nasmhpd.org)



Bulk copies of 11 or more are available at \$10/copy. Once released, the report available at the following Website: <http://www.nasmhpd.org/ntac/reports/index> PDF format.

## **Mental Health Recovery: What Helps and What Hinders? Executive Summary**

### *Mental Health Recovery: What Helps and What Hinders?*

A National Research Project for the Development of Recovery Facilitator System Performance Indicators evolved from collaborative efforts of a number of State Mental Health Agencies (SMHAs). These states were interested in developing a measure related to recovery as one of a number of indicators that can be used to assess the performance of state and local mental health systems and providers. The specific aims of this project were to:

- ☛ increase knowledge about what facilitates or hinders recovery for people with psychiatric disabilities;
- ☛ devise a core set of systems-level indicators that measure critical elements and processes of a recovery-facilitating environment;
- ☛ integrate items that assess recovery-orientation into a multi-state "report card" of mental health system performance measures in order to generate comparable data across state and local mental health systems and encourage the evolution of recovery-oriented systems.

This Phase One Report describes the findings of the first specific aim of the project. Structured focus groups and qualitative research methods were used with a diverse cross-section of consumer/survivors. Ten focus groups were held in nine states to gain knowledge on what helps and what hinders mental health recovery. All concepts and findings are based on the maximum degree possible, on the audio-taped words of participants. The five-person research team, each with significant recovery research

experience, posited at the outset five important domains of recovery: resources/basic needs, choices/self-determination, independence, interdependence/connectiveness, and hope. Themes and data encompassing mental health services staff and the mental health system as a whole were also analyzed. Research participants, N=115, constitute a purposive sample that encouraged diversity. Thus, we systematically elicited insight and knowledge on mental health recovery from a diverse and broad base of consumer/survivors across the nation.

The research team used a process of qualitative coding, codebook development, cross coding, and recoding to develop a single set of findings across all of the groups. After coding each unique response, we compiled the responses thematically, first according to questions and second according to emergent themes. These themes include the following and other emergent themes: basic material resources, self/whole person, hope/sense of meaning and purpose, choice, independence, social relationships, meaningful activities, peer support, formal services, and formal service staff.

While recovery is a deeply personal journey, there are many commonalities in people's experiences and opinions. The findings presented are comprehensive. We had to work hard to reduce the 1,000 pages of transcript data to a manageable set of themes, and some richness, nuance, and personal stories unfortunately are lost in the reduction processes. In fact, recovery is facilitated or impeded through the dynamic interplay of many forces that are complex, synergistically linked.

A conceptual paradigm for organizing and interpreting the phenomenon of mental health recovery is beginning to emerge from the study findings. Recovery is a product of dynamic interaction among characteristics of the individual (the self/whole person, hope/sense of meaning and purpose), characteristics of the environment (basic material resources, social relationships, meaningful activities, peer support, formal services, and service staff), and the characteristics of the exchange (hope, choice/empowerment, independence/interdependence).

Within this ecological context, basic material resources, such as livable and safe and decent housing, healthcare, transportation, and a means of communication (e.g., telephone), move people toward recovery. Failure and the lack of basic resources undermine a sense of safety and hinder people back in their recovery.

Concurrent with basic material needs, people need opportunities and supports to engage in the responsibilities and benefits of citizenship and membership to community. Recovery involves a social dimension,

of active, interdependent social relationships being connected through families, friends, peers, neighbors, and colleagues in mutually supportive and beneficial ways. Social and personal isolation, poverty, emotional withdrawal, controlling relationships, poor social skills, immigrant disabling health and mental health conditions, past trauma, and stigma impede the recovery journey.

Full citizenship expands beyond social relationships, however. Participants indicated that recovery is enhanced through engaging in meaningful activities that connect one to the community. Often this can be achieved through a meaningful job and career, which can provide a sense of identity and mastery. Participants also identified other options, such as advancing one's education, volunteering, engaging in group advocacy efforts, and/or being involved in program design and policy level decision making. Participants report high rates of unemployment, underemployment, and exploitation. Training and education opportunities are lacking, benefits have employment disincentives, prejudice and discrimination hamper efforts, and individual wishes and decisions are disregarded.

When considering both the basic material needs and citizenship dimensions to recovery, we are struck by how generic and universal responses were. Just like any group of American adults, the respondents included a compelling belief in the 'American Dream' of economic opportunity, self-sufficiency, liberty, and the pursuit of happiness.

Our findings support personhood serving as another critical dimension to recovery. Participants talked about the internal sense of self, inner strivings and their whole being (physical, emotional, mental, and spiritual) as affected by and affecting the recovery process.

They described various personal qualities, attitudes, and conditions that can help (self-reliance, personal resourcefulness, self-care, self-determination, self-advocacy, holistic view) or hinder (not taking personal responsibility, shame, fear, self-loathing, invalidation, disabling health and mental conditions).

The personhood dimension is also about hope, purpose, faith, expectancy, respect and creating meaning. Participants described developing a sense of meaning, purpose and spirituality as well as goals, options, role models, friends, optimism, and positive personal experiences support recovery. Demeaned dreams, pessimistic status quality services, discounted spirituality, poverty, unwanted and long psychiatric hospitalization, and lack of education and information about one's condition and potential resources destroy hope and act as roadblocks to recovery. All have powerful negative effects on individuals.

self-concept, esteem, and sense of efficacy. These effects are compounded by mental disorder itself and the associated stigma (internalized and external), prejudice and discrimination.

Believing that recovery is possible and having this belief supported by others (friends, family, peers, and staff) helps fuel self-agency (the process of intentionally living one's life on one's own accord). Part of what people want to understand what they are experiencing, they want to be educated, have good information and actively participate in making important choices. It is also important to note that some of our findings seem to indicate that certain cultural affiliations, such as tribal community, may modify the emphasis on self-agency through acts of kinship or tribal mores that stress interdependency or living for the benefit of the larger social unit.

When considering the fullness of the personhood and self-agency dimension to recovery, we are again struck by how such findings reflect a universal quality of life needs and desires. Participants' life journeys began prior to the onset of mental illness and continue after. Hope and hopefulness advances many participants' life journeys. Thus, a holistic focus on positive expectancy (regarding attitudes, beliefs, and goals) on the part of helpers, within families, and in the media and broader community can move recovery forward.

Empowerment is another critical dimension of recovery. The goal of empowerment becomes one of people gaining power and control over their lives through access to meaningful choices and the resources to implement those choices. Our findings document the crucial role that choice plays in empowerment. Having information on, and access to a range of meaningful and useful choices and options fosters recovery. Participants are empowered when they make the choices regarding where they live, housing, finances, employment, personal living/daily routine, disclosure, who they associate with, self management and treatment. Individual participants talked about the empowering experience of choosing 'how I see myself, my disorder, my situation, my quality

of life. But for such empowerment to occur, meaningful options must exist. People must have training and support in making choices, and the freedom to take risks and fail. Too often quality of life choices seen outside the realistic reach of many participants. Options are limited, lousy, or nonexistent.

Participants recounted service providers, professional and family members and communities that responded through the use of coercion, control, restricted access or involvement, discrimination, and stigmatization. Independence (not being subject to the control of

and not requiring or relying on others. -*Webster's II New Riverside University Dictionary, 1984*) also falls within the empowerment dimension. Participants expressed it as both a process and goal of recovery.

Independence is achieved through making one's own choices and decisions, exercising selfdetermination (such as advanced directives, enjoying basic civil and human rights and freedom, and having a living income, a car, affordable housing, etc. Paternalistic responses, lack of respect, involuntary and long-term hospitalizations, stereotyping, labeling, discrimination, the risk of losing what benefits and support does have, all undermine independence. Repeated encounters with negative experiences instill fear, lack of confidence, and negative attitudes and beliefs.

Some participants talked of the importance of both independence and interdependence, reaching beyond the goal of independence to embracing interdependence. Interdependence is a term that implies interconnection or an interrelationship between two entities and is used to describe the link of people to people. Seeking independence and supporting interdependence are not mutually exclusive.

The mental health self-help and consumer/survivor movement promotes self-referent power opportunities. The need for a large-scale expansion of funding, support and availability of peer services, such as peer support, education, outreach, role models, mentors, and advocates was a common theme across all focus groups. Participants identified the need for alternative services and 'experienced experts/peer specialists' employed across all levels of mental health service provision. Limitations in funding, geographical availability, participation, and leadership development opportunities, as well as lack of transportation, and controlling and mistrustful professionals hinder peer support efforts.

The formal service system, and the professionals and staff employed within it, constitute another dimension that impacts recovery. We see that progress toward recovery can be supported through the formal system. There was, however, much more 'hindering' content within the data regarding formal systems than any other domain.

We must fully acknowledge that the formal system often hinders recovery through bureaucratic program guidelines, limited access to service supports, abusive practices, poor quality services, negative messages, lack of 'best practice' program elements, and a narrow focus on a psychiatric orientation that can actually serve to discount the person's humanity and ignore other practical, psychological, social, and spiritual human needs. At the core of such hindering forces is the

operationalization of society's response to mental illness, that of shame and hopelessness and the need to assert social control over the individual and uncomfortable.

Many of our findings lend further support to shortcomings already identified within the formal system of care. Often these hindering influences are the unintentional consequences of procedures implemented by well-meaning authorities in a belief that the practices are in the interest of patients. People have basic subsistence needs that 'the net' does not meet. Social welfare and mental health programs are fragmented and difficult to access. People do not want to have to deteriorate in order to receive help, nor do they want to lose vital supports when they make progress toward recovery. Psychiatric services can be experienced as a means of social control, countering individual efforts of recovery.

The experience of trauma and abuse was also notable across the four groups. The impact of the status of the mental health patient comes through in our findings through the discussion of internalized stigma, repeated traumatizations by the system, and the historical trauma of abuse. The formal service system and many of its personnel largely overlook how responding to, and coping with, trauma is a central experience of psychiatric disorder and thus the system fails to incorporate trauma knowledge in existing explanations of, and responses to, mental illness. Pivotal in creating a culture of belonging, safety, openness, participation, citizenship, and empowerment is the large-scale support of peer services and peer staff, both independent of and integrated into existing service delivery systems.

Another critical change involves the need to return to the basic concept of helping, a 'therapeutic alliance' the need for positive helping relationships based on partnership. People do not want to interact with neutral or detached helpers, nor do they want to meet a new professional or paraprofessional each time they seek help. Opportunity for choice and negotiation in selecting partnership relationships with a doctor, therapist, or case manager were strong concerns. People desire the collaborative development of individual treatment plans with full information on potential benefits and side effects of medication. Most people sought to continue to be in charge of her or his treatment or recovery plan to the maximum degree possible and to exercise choice in all aspects of their lives, sometimes through the use of mental health care proxies or advance directives. They want to have people care for them and listen to them and empower them. Respect becomes critical. The whole focus of the helping relationship should have this value at its core; the actualization of the individual through self-determination and choice.

Recovery can be construed as a paradigm, an organizing construct that can guide the planning and implementation of services and support for people with severe mental illness. The outlines of a new paradigm recovery-enhancing system are emerging. Such a system is person-oriented, and respects people's lived experience and expertise. It promotes decision making and self-responsibility. It addresses people's needs holistically and contends with more than their symptoms. Such a system meets basic needs and addresses problems in living. It encourages people to move toward self-management of their condition. The orientation is one of hope with an emphasis on positive mental health and wellness. A recovery-oriented system assists people to connect through mutual self-help. It focuses on positive functioning in a variety of settings and building or rebuilding positive relationships.

The work of Phase One of this project constitutes a rich and complex fabric of findings for use in formulating future research, including the construction of evaluation tools to examine mental health system performance as to how well local and state mental health systems promote or facilitate mental health recovery. It is clear that the way we configure mental health and social service policies, formal mental health services and the day-to-day informal cultures that exist within programs and systems can serve to either promote or inhibit recovery. The following are key implications of the findings.

- ☛ Since persons are at the core of a dynamic interplay among themselves, other people, the resources available in the environment, and other forces, mental health services must recognize and allow for self-agency while bolstering, or at least not undermining, such efforts. Seeing people as whole persons beyond their labeled identity is integral to recovery.
- ☛ A shift to a recovery orientation will require attention to well-being and health promotion, not simply attention to symptom suppression or clinical concerns. Attention must be paid to basic needs in areas such as food and affordable housing, health care, income, employment, education, and social integration.
- ☛ A recovery orientation will require close attention to fundamental rights and needs. Re-orientation away from coercion requires alternative resources as well as training.
- ☛ There needs to be a continual evolution in our thinking, and the development of knowledge concerning recovery among diverse communities. For example, the balance of autonomy and self-reliance versus group or family focus may differ in recovery efforts based on such factors as ethnicity and culture. Special attention is required for these differences.

for people who have experienced trauma or who have substance disorders.

- ☛ Resources for re-educating families, consumers, the professional, paraprofessional providers, young people, and the public at-large. The potential for recovery are called for, and will take significant investment. Stigma and misinformation must be countered through a variety of strategies (with attention to incorporating active participation for consumer/survivors) that target many audiences.
- ☛ Hope and empowerment are critical and their relationship to recovery warrants further research attention.
- ☛ True parity of decision-making power and respect through mutual and supportive partnership among consumer/survivors, professionals, administrators, and policy makers can become the basis of collaborative efforts to design and implement action strategies that will move America's mental health systems to recovery orientation. Adequate resources are needed to fund support consumer voice and consumer leadership development.

Several factors contributed to the limitations of this study. Recruitment had limited representation of age, ethnic and cultural diversity. The recruitment process in all states entailed self-selection and is not fully representative of the population of public mental health system recipients. The size of the focus groups, which exceeded the optimum, have somewhat limited individual participant opportunities to share insights and observations. Focus group methodology limits identification of consensus as well as the themes or domains that are most or least important.

The long-term goal of this research project is the development of a set of systems-level indicators that measure critical elements and processes of a recovery-facilitating mental health service environment. Phase Two of this work, the findings of Phase One will be utilized to comprise a set of prototype performance indicators. In Phase Three, the resulting measure will be pilot-tested across multiple sites.

Source: <http://www.nasmhpd.org/ntac/reports/MHSIPReport.pdf>

---

This 'Mental Health E-News' posting is a service of the New York Ass'n of Psych Rehabilitation Services, a statewide coalition of people who use and/or provide community mental health services dedicated to improving services and social conditions for people with psychiatric disabilities by promoting their recovery, rehabilitation and rights.

To join our list, e-mail us your request and, where appropriate, the name of your organization.

organization to [NYAPRS@aol.com](mailto:NYAPRS@aol.com).

Last Updated on 01/06/03 [webmaster@namiscc.org](mailto:webmaster@namiscc.org)



Opinions expressed in this web site do not necessarily reflect the views of NAMI Santa Cruz County, NAMI California or any affiliated organizations. We attempt to present a balanced perspective on issues by presenting multiple viewpoints.

Copyright 2004 National Alliance for the Mentally Ill Santa Cruz County, All Rights Reserved.

FAIR USE NOTICE: This may contain copyrighted (©) material the use of which has not always been specifically authorized by the copyright owner. Such material is made available to advance understanding of ecological, political, human rights, economic, democracy, scientific, moral, ethical, and social justice issues, etc. It is believed that this constitutes a 'fair use' of any such copyrighted material as provided for in section 107 of the US Copyright Law. For more information go to: <http://www.law.cornell.edu/uscode/17/107.shtml> If you wish to use copyrighted material for purposes of your own that go beyond 'fair use', you must obtain permission from the copyright owner.